Decision-Making Surrounding Infants at the Margin of Viability:

Understanding Family-Provider Interaction

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Abstract

With advances in technology over the past few decades the characteristics of an infant considered to be at the margin of viability has changed markedly. Medical interventions are now able to help sustain the life of infants born at gestational ages as young as 23 weeks and at higher acuity levels than previously seen. The birth of infants at the margin of viability has raised serious ethical questions regarding survival, parenting, and suffering. These questions challenge the way in which we view the interactions between the family and the providers in making decisions surrounding the infant's care. Each party, the family and the providers, share concern in promoting the best interest of the infant. However, with differences in expertise, experience, and guiding ethical frameworks the two parties have the potential to hold contrasting views on the care of the infant. Further research on the process of regoaling and the incorporation of the collaborative communication model in provider education may benefit future conversations and family-provider interactions in cases of birth at the margin of viability.

Introduction

In the United States approximately 520,000 infants are born prematurely – prior to 37 weeks gestation -- each year (World Health Organization, 2015). Advances in technology have promoted the survival of infants born at progressively younger gestational ages, including extremely premature infants of less than 28 weeks gestation. Extremely premature infants between 22-25 weeks of gestation are considered to be at the margin of viability. Research has shown that infants between these gestational ages require more intense medical intervention to sustain life and poorer long-term outcomes than infants born even a week later (Bastek, Richardson, Zupancic, & Burns, 2005). Infants born at the margin of viability foster the hope of survival, create ethical dilemmas, and raise serious questions surrounding parenting, survival, and suffering. In a time where families and providers are seen as a partnership the care of these infants challenges the way in which we see providers and families working together to make decisions. In order to gain an understanding of current issues in neonatal nursing related to parental decision-making regarding their infants born at the margin of viability, the purpose of this paper is to review 1) the processes through which parents make decisions surrounding infants at the margin of viability and 2) the role of health care professionals, specifically nurses, in these decisions. This knowledge will provide a comprehensive foundation for the development of clinical guidelines in bridging physical and emotional support to reconnect with our ideal of holism.

The Margin of Viability

Viability is a term that lacks a universal definition, leaving health care providers to determine which characteristics suggest that the infant is viable. The margin of viability is

typically the gestational age between 22-25 weeks (Chiswick, 2008); however, recent literature has pushed for the inclusion of other criteria in defining viability (Tyson et al., 2008). Though often not accounted for, the presence of overwhelming illness or congenital anomalies that are incompatible with prolonged life also place an infant at the margin of viability (Leuthner & Lorenz, 2008). In this paper, the margin of viability refers to any infant who requires medical intervention, even temporarily, to sustain life regardless of their individual clinical characteristics (Baer & Nelson, 2007).

Ethical Considerations

Ethical Theories. Theories are often used to describe, define, predict, explain, and control everyday happenings. Many theories have been used to define morality and a sense of right and wrong. Common theoretical frameworks familiar to providers in the health care setting include: deontology, utilitarianism, and virtue ethics. Deontology and utilitarianism are act-centered theoretical frameworks. Deontology is the theory that the morality of an action is dependent on its adherence to rules and one's obligations (Moreland, 2009). In the case of an infant at the margin of viability this would mean evaluating the morality of a treatment option based on whether or not the treatment provided was within the hospital protocol and if it fulfilled the duties of the care providers, without regard to the intentions nor to the outcomes of the treatment. Conversely, utilitarianism (also known as consequentialism) infers that morality is based on the consequences or outcomes of the act, without regard to the intent or motive behind it (Moreland, 2009). In suggesting that the outcome of an act holds moral significance, utilitarianisms hold that the outcome of treatment is the focus in evaluating the ethics of care that an infant receives (Wiley-Blackwell, 2013).

In dealing with a dilemma as complex and variable as treatment of infants at the edge of viability one requires a person-centered, rather than act-centered theory. Virtue ethics, a person-centered theory, focuses on judging the morality of an action by comparing it to the actions of a virtuous individual with the same set of circumstances (Black, 2011). Virtue ethics calls on the presence of phronesis or practical wisdom. Phronesis implies that virtuous persons hold the capacity to judge the right means to the good end. The use of phronetic thinking requires the cognitive construction of that which is meaningful (Carnevale, 2007). The process of meaning making and the use of practical wisdom infers that families and providers must establish their perception of the infant's status, determine a goal, and act according to the infant's best interest. The use of these frameworks and the determining of an infant's best interest are conducted through the use of general ethical principles.

Ethical Principles. The care of extremely premature infants is guided by the professional ethic of the provider. Professional ethic refers to the framework of ethical standards that guide the behavior of individuals within a particular profession (Nelson, 2006). Professional ethics do not take the place of personal ethics or general ethical principles; however they serve as the primary ethical guidelines for resolving conflict within a profession (Nelson, 2006). Professional ethics is influenced by the literature and attends to the principles of autonomy, veracity, faithfulness, justice, beneficence, and nonmaleficence (Beauchamp & Childress, 2009; Butts & Rich, 2008). These are concepts that shape the care that the health care team provides in all situations. Autonomy refers to the right of an individual to determine their own actions and exercise the freedom of choice in making decisions surrounding their care. In the circumstance of an infant, the family as the legal guardian stands in as the decision maker. Veracity is the principle of truth telling or not lying (Beauchamp & Childress, 2009).Veracity is pertinent to the

development of trust between the health care team and the family who must work cohesively to determine the care that is in the best interest of the infant. This requires bidirectional communication with the family receiving truths regarding the current medical status, likely prognosis, available treatment options, and future implications of their infant. Likewise, veracity requires that families offer providers transparency in addressing family preferences and capabilities (such as monetary resources and time).

Fidelity is the honoring of commitments or promises one has made (Beauchamp & Childress, 2009). Health care providers are to uphold their commitment to respecting all individuals and providing care that reflects their respective code of ethics. Faithfulness is an important principle in maintaining trust in the provider-family interactions. Research has shown that families who trust their providers are have a higher rate of satisfaction in the overall experience regardless of the outcome (Moro et al, 2011).

Justice or fairness is the principle that equals are treated the same and unequals are treated differently (Butts & Rich, 2008). This is a particularly interesting principle when considering the treatment and care provided to infants at the margin of viability. Following the principle of justice in a clinical sense would mean that infants who present the same medically should receive the same care and infants who presented with differing medical circumstances should be treated differently. This principle takes on a new level of complexity when the social and ethical aspects of caring for these young infants are considered. Much of the ethical debate surrounding the treatment of these infants rests in the incongruences within the treatment preferences and long-term perspectives of the families.

Beneficence is the principle of "doing good" (Beauchamp & Childress, 2009). Beneficence requires that the decision making process is built on the main priority of promoting good for the infant. Beneficence, though universally known as doing good, may present in different ways depending on the situation, specifically in addressing the treatment needs of an infant at the margin of viability. For one family, promoting good may be equated to supporting life at all costs because there is a belief that life is worth living regardless of the context surrounding that life. For another person, doing good in the same situation may entail withholding or withdrawing treatment to prevent harm and allow a peaceful passing in the presence of loved ones.

The last principle commonly described in the literature is nonmaleficence or the standard of "first do no harm" (Beauchamp & Childress, 2009). Both parties must avoid acting in a way that would intentionally cause harm to the patient. The family and the provider are obligated to advocate and act as guardians of the infant's best interest. The decisions made about the care of the infant should evolve from the need to minimize suffering first and foremost, prior to the initiation of care that is intended to yield an additional benefit.

Ethical Challenges

These guiding principles and common frameworks are incorporated into the health care setting to serve as the infrastructure for providing high quality care. Within certain health care settings the use of these frameworks and principles is imperative due to the complex medical and ethical nature of the situation. Infants born at young gestational ages and at the margin of viability have raised much debate revolving around ethical concerns of survival and suffering. Two major conflicts that give rise to these concerns are the ability to define the severity of an

infant's illness in reference to their sustainability and the benefit provided by treatment in relation to the potential harm caused.

Defining illness severity encompasses the judgment of viability as it relates to the probability of survival and of the probability of a severe disability in the long-term. The probability of survival is a subjective estimation based on the individualized assessment of the provider (Yates, 2008). One of the largest ethical considerations in the situation of an infant at the margin of viability tests the principle of nonmaleficence in weighing the benefits of care against the possible harms of the treatment (Carnevale, 2007). An ethical dilemma arises when gauging the advantage of promoting life against the disadvantage of prolonging pain or suffering. The degree of acceptable functionality is subjective and highly dependent on familial preferences (Ginsburg & Rapp, 2013). There is some ethical discrepancy is determining what level of disability is not only tolerable to the family, but also appropriate for the future functioning of this infant in society. The potential benefit of treatment against the likelihood that it may prolong or serve as the source of pain for an infant is another ethical dilemma (Baer & Nelson, 2007). How do we determine if an infant is suffering? What level of suffering is acceptable when maintaining life for these infants?

The Stakeholders.

Stakeholders are the individuals who have an interest in the care and well-being of the patient, in the case an infant that is on the edge of viability (Potts & Mandleco, 2012). The stakeholders are those responsible for weighing the various sides of each ethical dilemma in drawing conclusions about the plan of care that suits the best interests of the patient. Forming the

support team for these infants is the family and the providers, each with their own stake in the infant's care.

The Family. The family is a complex and dynamic stakeholder in the care of the infant. What constitutes as one's family varies from situation to situation. The legal system establishes guardianship, typically the parents, who are the fundamental stakeholders who have decision-making power in the infant's treatment. By law, parents are held responsible for acting in the infant's best interest; if it is deemed that the parents are unfit to make these decisions or are making decisions that do not reflect the infant's best interest the infant can then be made a ward of the state (Yates, 2008). When an infant becomes a ward of the state there is a third party stakeholder introduced into the decision making process, who now holds decision making power

Extended families can have influence, if not legal power, over decisions related to the care of these infants. Families are often defined by a sense of social connectedness that may be a result of shared legacy, rituals, religion, and/or genetics. This sense of connectedness that stems from shared experience forms bonds that are congruent with those often attributed to family ties.

The Providers. Providers are the members of the health care team that are involved in the care and treatment of the infant. This includes surgeons, maternal-fetal physicians, obstetricians, neonatologists, pediatricians, nurse practitioners, and nurses. The role of each of these providers varies depending on their involvement in the care of the infant and the setting in which care is taking place. Obstetricians may have a stake in the health and well-being of the infant that is concentrated during the time of pregnancy and in the delivery of the infant, usually providing out-patient care to the mother from a clinic standpoint. After birth the surgeons, maternal-fetal physicians, and the neonatologists take a primary role in the health and treatment

of the infant within the hospital. The surgeon's main priority is to successfully perform the necessary surgeries that were decided upon with the family. They aim to "fix" or create a solution to any and/or all physical complications that the infant may have. The fetal-maternal physicians' and neonatologists' primary role is to provide their medical expertise and professional opinion of the infant's physical state. The timing, whether pre or post-natal, will determine which specialist's expertise are required or deemed most beneficial. Nurses, including registered nurses and advanced practice nurses, work closely with the families, help families to break down information, act as an advocate and a liaison between the physician and the family, and provide the physical and emotional support that is needed by the family.

Shared interests among stakeholders. The members of the infant's support team play a major role in the care of the infant, each with their own interests in the outcome of the situation. Though the family and the providers occupy different roles in the infant's care their interests often overlap. Both parties are ultimately interested in the well-being of the infant. Many patients or families prefer not to assume full responsibility in the decision making process surrounding their care or the care of a loved one (Charles, Gafni, & Whelan, 1997), preferring instead to make joint decisions with insight and advice from the health care providers. The shared decision-making model and the collaborative communication model have become prominent in facilitating family-provider conversations that enable mutual conclusions about the patient's best interest (Charles, Gafni, & Whelan, 1997; Feudtner, 2007). The shared decision-making model necessitates the involvement of two parties that actively participate in the decision making process by openly sharing information and forming a conclusion that both parties can agree on (Charles, Gafni, & Whelan, 1997).

The collaborative communication model requires the establishment of a common goal, the presence of mutual respect, the understanding of differing perspectives, the assurance of maximal clarity in communication, and the management of the processes that affect how an individual sends, receives, and processes information (Feudtner, 2007). These two models guide the process of decision making and the communication techniques used throughout the process. Providers and families must compromise on a treatment option that parallels both ethics, given their unshared experiences and potentially differing views of what is in the infant's best interest. Though the two stakeholders share the common principle of beneficence in promoting the infant's best interest there is some difficulty in implementing the shared decision-making model and the collaborative communication model due to an imbalance of knowledge, control, and expertise in the family-provider relationship (Feudtner, 2007). With knowledge and expertise in favor of the providers and legal control in the favor of the family it is problematic when one party's assessment of the infant's best interest does not parallel the other party's assessment.

Varying interests among stakeholders. Beyond the common goal of promoting the infant's best interest the two parties have different concerns regarding the infant's treatment. Families may be confused in understanding the survivability, potential disability, and the suffering of the infant. Distress in the ability of the infant to overcome the presenting complications in order to sustain life is an innate reaction by families (Kavanaugh, 1997). Families struggle with the uncertainty of the diagnoses, the treatment, and the outcomes that accompany an infant at the margin of viability. In pursuing medical intervention the family is then faced with the possible sequelae of treatment and prolonged life. Families question the level of disability or range of function that the infant will have to live with if medical treatment is successful in maintaining life (Ginsburg & Rapp, 2013). Suffering is then a concern for parents

in both the immediate and future circumstances. Families experience anxiety with the possibility that the infant is currently suffering due their medical complications or the interventions being initiated, as well as future mental and emotional suffering related to the sequelae of their complications and their medical treatments (Moro, Kavanaugh, Savage, Reyes, Kimura, & Bhat, 2011).

Providers hold the medical knowledge and expertise necessary to assess the needs of the infant, develop a list of treatment options, and relay this information to the family. With their reservoir of knowledge and their experience in treating other infants of similar medical statuses the providers bring a specific perspective the table. Providers have taken an oath to uphold their professional code of ethics and provide the best medical care within their ability (Finlay, 2006). Providers' work is related to their obligation to follow their code of ethics, as well as to their desire to produce the best possible outcome for the infant (Cuttini, 2000). Providers, in their faithfulness to the infant and to the family, aim to provide care that will yield the best or the preferred outcome as understood through the family-provider interactions. At times providers' practice is hindered by the reality of the economic burden that medical treatment can have. In cases where providers understand that a poor prognosis is likely they juggle the ethical dilemma of whether continuing treatment to comply with familial preferences is worth the financial debt that caring for the infant is placing on the family and the community. While financial constraints are not something that many families want to consider in deciding upon their infant's plan of care it has a huge impact on society as a whole and on the future of the family.

Components of Care

Addressing the subjectivity with which providers assess medical circumstances and evaluate potential treatment options begs the question of inclusion and informed consent. What are the key elements of the infant's situation that must be known before one has enough knowledge to act? We are asking what pieces of information must be included in the provider-family conversation to constitute a true informed consent for both stakeholders. In order for the support team to accurately assess the situation and agree on the appropriate method of treatment they must all have equal access to the information related to the infant, including: 1) the current medical status (diagnosis and prognosis); 2) all possible treatment options; 3) all possible outcomes; 4) family preferences; and 5) family capabilities.

Current medical status. Understanding the current situation of the infant involves the discussion of the diagnosis and prognosis; the current stability of the infant and resources being utilized; and the potential changes or courses that the infant may experience/take given their current status. The first, diagnosis and prognosis, consists of the statistical information relating to the infant's medical condition. This evidence-based information is an objective and tangible portrayal of the situation that provides a foundation or baseline for providers and families to assess their goals. The second, current stability and resources being utilized, encompasses the current medical acuity of the infant and calls attention to the time, money, and space being occupied and the implications of the medical interventions in action. This quantifies the impact of the care being received and provides a longitudinal view in attempting to show how the infant's status has progressed up to the current time. Finally, discussing the potential changes or courses that the infant may experience given their current medical status is instrumental in promoting a longitudinal view of the infant's care. While this discussion overlaps with the

statistical information provided in regard to prognosis, the discussion of potential outcomes and future implications of current medical treatment illustrates a realistic view of the infant's life should they survive the present medical complications.

Treatment options and possible outcomes. The discussion of potential treatment options is a conversation that should include all available options for care that could realistically benefit the life of the infant without omission of any treatment based on the values or beliefs of either party. Following the broad spectrum discussion of available treatment options the family-provider conversation can then be narrowed to focus only on those treatment options that have an adequate likelihood of producing the desired outcome as agreed upon by the support team. Each discussion around the potential treatment options should be accompanied by a dialogue about the possible outcomes related to the individual treatments. Families and providers need to have full comprehension of not only the treatments, but also the implications and possibilities with each of them. In the event that a potential outcome or complication of a treatment is not worth the potential benefit this would have a significant impact in the treatment that was chosen.

Family preferences. The family, as the legal decision makers in the care of an infant at the margin of viability, have the final say in the treatment that the infant receives (assuming that this decision is not one of neglect or maltreatment and could arguably be in the child's best interest), being so the familial preference serve as a foundation for analyzing treatment options. Providers must have information regarding the hopes and goals of the family, their willingness to consider alternative goals and treatment options, and the circumstances and treatments that are intolerable to them. This range of knowledge provides not only a starting point for the decision making process, but serves as the infrastructure in continued decision making as the medical status of the infant evolves through time and treatment.

Familial capabilities. Lastly, the family-provider conversation must include a discussion around the capabilities of the family. What is their financial situation? How will their family dynamics adapt to the inclusion of this infant who requires significant medical attention? Financial concerns arise with the understanding that treatment as an inpatient and then as an outpatient is expensive. Will this family be able to financially support this infant at the level of anticipated disability given their current status or are their means by which the family can continue to support this child throughout what life they may have? What is the family dynamic like? The family and the provider must consider not only the financial constraints and the impact that it may have on their lives, but also the impact that the time, money, and effort spent on this medically dependent infant will have on their other children, their careers, and the lifestyle that they may require.

Using collaborative communication principles to fully disclose and discuss diagnosis, prognosis, treatment options, potential outcomes, family preferences, and familial capabilities regarding care promotes transparency in the provider-family interaction (Feudtner, 2007). Given the amount and density of this exchange of information, in addition to the emotional state of the family, it is expected that the interpretation of the information differs between the two parties. There is an expected level of medical knowledge that is required to comprehend the severity of the infant's medical status and analyze the implication of the treatment options being considered.

Research has shown that nurses are the main sources in providing emotional support, giving information, and meeting the physical care needs of the family (Kavanaugh, Moro, & Savage, 2010). It is in viewing the decision making process from this perspective that sheds light on the impact of nurses, in particular, in these circumstances. As the member of the health care team that spends the greatest amount of time with the family it is no surprise that nurses have a

unique role in assisting families through the decision making process. In working so closely with families nurses gain the knowledge that is invaluable; they learn about family preferences, rituals, concerns, and styles through conversations and continuous nonverbal interactions.

Scenario

A male neonate is admitted to the neonatal intensive care unit (NICU) immediately following delivery. He was born at an estimated 24 weeks gestation and is extremely premature; he weighs 675g (approximately 1.5lbs). Upon admission to the NICU the family expresses their desire for all interventions available to be initiated. They are asking that "everything" be done to help the infant sustain life. Following admission the infant continues to experience complications related to his premature birth, including: respiratory difficulties due to the lack of surfactant at birth, temperature control issues, feeding difficulties, anemia, jaundice, hypo- and hyperglycemia, and numerous infections because of his immature immune system. The NICU health care providers continued to maintain the infant's status as a full code (i.e. to have full resuscitation in case of cardiac or respiratory arrest) and to use all available resources to help the infant survive. Despite vigorous effort by the health care team the infant suffers a grade IV (on a scale of I-IV, with IV being the most severe) intraventricular hemorrhage (IVH) and has bled into the ventricles and surrounding tissues of his brain, which causes him to require maximum intervention to live. The provider understands the implications of this type of bleed; she discusses the current status of the infant and the high probability of physical and cognitive disabilities if the infant survives. Given the infant's grave condition, the provider introduces the option of withdrawing his life support. The family decides that the life of the infant is their highest priority and they are willing to accept any and all complications that may arise if he survives. The nurse, who has been working closely with the family since they first arrived in the

NICU, is empathetic to the family's desire to maintain hope that the infant will live and to continue life support efforts, but she recognizes the ethical issues that the provider is facing in performing care that may not fit within her professional ethical boundaries. Both parties (the family and the provider) worry about the potential pain and suffering of the infant; however their assessments of the risk and benefits of continuing life support differ because of their contrasting backgrounds.

Outcome A. The providers continue to maintain life support measures as the infant begins to feed and grow. As the infant progresses the providers work to eliminate the use of unnecessary medical equipment. Due to the injuries sustained with the IVH the infant has feeding difficulties, respiratory complications, and suspected neurological deficits. After 5 months in the NICU the infant is discharged home with numerous supportive technologies, including oxygen and a feeding pump. The case manager has arranged for out-patient services to help manage the infant's care at home, including a home health nurse specializing in pediatric care. The providers believe that it is unlikely that the infant will ever come off of the feeding pump and the oxygen according to his history and current medical state.

Outcome B. The providers continue to maintain life support measures, but a week later the infant develops sepsis, has a cardiac arrest event and subsequently dies during efforts to resuscitate him. .

Discussion

When infants are born extremely premature or with significant complications families are challenged with assisting in the decision-making process surrounding the infant's care. Both the families and the providers are guided through the decision making process with their own values

and beliefs, which are shaped by various ethical principles, frameworks, and their personal experiences. While each party has a primary priority in promoting the best interest of the child, each stakeholder navigates the decision making process with a different reservoir of knowledge and concern. Merging these two perspectives in final decision making is complex and can compromise the quality and efficacy in the care that is provided to the infant and have a lasting impact on the lives of the caregivers.

With the priority of care grounded in the desire to provide the best medical care possible with minimal amount of suffering, providers and families must start by establishing a goal from which to base their efforts. It is common for families to advocate for having "everything done" in the initial stages of birth or new diagnoses with the hope of having a happy and healthy infant as the end result (Moro, et al, 2011; Hill et al., 2014). As illustrated in the scenario above, the family originally opted to have all necessary interventions initiated to maintain their initial hopes of a healthy and viable infant. Though not always able to reasonably expect the outcome of an infant with optimal health families can expect that their health care team will provide the best care in favor of the family's outcome preferences. As the infant's medical condition evolves and the family-provider conversation continues here raises the potential for both parties to recognize that the initial goal, the goal of having a healthy infant, may no longer be attainable or realistic. The scenario, though fictional, displays the differences in perspective that may arise in the care of an infant at the margin of viability. As the infant remained on life-support in the NICU he suffered many complications that caused the providers to reevaluate the current course of treatment; however, the family expressed the desire to pursue the original plan of care.

From this point the decision making process can take one of two paths. In the first path the family chooses to pursue the initial goal in continuing to implement aggressive treatment

even with the knowledge that this goal is no longer viewed as realistic by the health care team, as displayed in the scenario. In the second path the family choses to accept that the changing characteristics of the infant's condition are no longer conducive to achieving the initial goal so they work with the most current information to develop a new set of goals (Hill et al., 2014). If the family in our scenario had chosen to take the second path it may have meant that the family agreed to discontinue the infant's life support and provide palliative care or the family opted to only maintain current supportive measures with the hope that the infant would progress from his current medial state. In these two scenarios the family has relinquished the hope for having a healthy infant and has reengaged with the hope of promoting comfort and/or preventing further suffering. This process of disengagement from goals, reengagement in new goals, and the hopeful thinking that accompanies each is what Hill et al. (2014) have referred to as" regoaling".

The process of regoaling requires not only the factors of disengagement, reengagement, and hopeful thinking, but also mandates the full use of collaborative communication between the family and the health care providers. Families can expect to be given all information relevant to their infant and afforded the time and the support to analyze their situation, construct their own truths, reframe their hope, and make calculated and confident decisions alongside of their providers (Brietbart & Heller, 2004). Given the lack of medical training, experience, and the heightened state of emotion of families in these situations it is understood that they require special attention and additional time to comprehend and analyze the meaning and severity of the infant's condition.

In communicating with providers, families should reasonably expect to be given all information necessary to make an informed decision. With this information the family is forced to construct a narrative that allows them to make meaning of the given circumstances and decide

how it interfaces with their lives (Breitbart & Heller, 2007). With the construction of a narrative the family is able to make sense of the situation and frame their hopeful thinking around the context of the infant's status. In our scenario the family was given all pertinent information related to their infant's care. This information led them into the process of analyzing the meaning of their infant's status, the implications of his care, and the circumstances that they can expect or hope for. The framing of hope provides the family with the confidence to relinquish initial goals by fostering their hope in a set of new goals that are thought to be more attainable (Hill et al., 2014). After analyzing their situation the family decided that their hopes were still tied to the survival of their infant so they pursued the original plan for aggressive medical treatment.

Providers interact with the family throughout the entire process by providing medical status updates, alternative routes of treatment, medical expertise, personal experiences, physical and emotional support, and hope – whether it is intentional or unintentional. The provider's role in this process is profound and has the potential to significantly impact the family's decision. The way in which the health care providers interacted with the family in our scenario had an impact on the way in which they progressed through their decision making process. Though it was clear that the providers believed the infant to have a poor prognosis, the support that they offered the family enabled the family to draw their own conclusions based on factual information. This objectivity and continuous support is highly influential during this sensitive process (Kavanaugh, 1997).

With legality on the side of the family and expertise in favor of the health care providers it becomes hard to discern which party has the largest influence on the treatment decision related to the infant. The ethical questions of the weight that each party's ethic should have in the decision making process and the influence of each of their expertise is often raised in debate

(Yates, 2008). Both parties offer information that is valuable to the decision making process. Health care providers offer information surrounding the current medical situation, the available treatment options, and the potential outcomes. The family offers information on their ability and willingness to care for the infant given the potential outcomes. Ideally, neither expertise carries more weight than the other, in this case both the provider and the family share similar values and outcome preferences. The decision would utilize the provider's expertise and experiences to analyze treatment options with full consideration of the familial preferences. However, in the clinical setting it is often the health care provider who has the majority of the information at their disposal.

Providers, with their training and experience have a vast amount of knowledge regarding a situation that families likely have little to no exposure to. In essence this shifts the decision making power toward the providers by enabling them to impact the decisions of the family through the manner in which they frame or deliver the medical information. The schemas that providers operate by may filter the type or amount of information that is offered to a family. What the family sees as a viable option for treatment may not even be considered by the provider. In our scenario the family was given the opportunity to make their decision without biased guidance of the medical expertise. In a contrasting scenario the providers may have chosen to present the discontinuation of life-support as the "only option", by using a select tone and vocabulary to paint a grim picture of the outcome of continuing life-support. Or the providers may have chosen to refrain from making life-support maintenance an option and focused their conversation with the family on the different alternatives in withdrawing life-support.

Implications

Decision-making surrounding the treatment and care of infants and the margin of viability is a complex process, one that challenges the integration of multiple ethical principles and perspectives and emphasizes the importance of the provider-family interaction in the process of decision making. Nurses, as part of the health care team, play a role in the exchange and interpretation of information regarding treatment. However, the roles of the nurse extends beyond their presence in medical conversations, they provide valuable emotional and physical support and act on behalf of the family in navigating what may be the unfamiliar territory of the health care system.

The collaborative communication model is the potential to serve as a standard in guiding the provider-family interaction. The principles of goal establishment, mutual respect, understanding of differing perspectives, assurance of maximal clarity in communication, and management of the processes that affect how an individual sends, receives, and processes information will open the dialogue between the family and the provider and provide transparency; both of which will work to promote trust and build rapport. Nurses having knowledge of the collaborative communication model could positively impact the decision-making process by eliminating some of the inadequacies of communication that may currently exist in the clinical setting. In strengthening the method of communication nurses can better give and receive information when interacting with families, this can promote both family and provider satisfaction throughout the decision-making process.

As with any sensitive or complex topic the ethical debates will continue. In the circumstance of an infant at the margin of viability the goal is to promote care that has the

greatest likelihood of producing an outcome that is in the infant's best interest. In an attempt to merge the ethics of both parties involved in the decision-making process it may be of benefit for the provider-family conversation to revolve around the core factors that ultimately influence treatment decisions (diagnosis and prognosis, treatment options, potential outcomes, family preferences, and familial capabilities). Nurses, in a unique position, as the front line in interacting with families are presented with the highest probability of obtaining this pertinent information. Promoting the development of guidelines that will assist nurses in addresses these topics with families has the potential to simplify the decision-making process for families and keep focus on the primary goal of providing appropriate care for the infant.

The process through which families comprehend the medical severity and make meaning of their infant's situation affects the force and direction of their hopeful thinking in establishing initial and secondary goals for care. Further research on the process of regoaling and the incorporation of this process in the education of nurses could assist nurses in understanding how families develop goals, recognize when their goals change, and help facilitate the process in appropriate circumstances.

Conclusion

The survival and treatment of infants at the margin of viability draws attention to ethical dilemmas surrounding parenting, survival, and suffering. Though there is much debate on the role of each stakeholder and the weight of their expertise in influencing the care of the infant, the decision-making process regarding their care is dependent on the active participation of both parties. Further research on the process of regoaling and its application to this decision-making process may help nurses and other health care professional better guide the family through decision making. The education and incorporation of the collaborative communication may also

benefit this process by facilitating effective and mindful conversations between the providers and the family.

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